Chronic Obstructive Pulmonary Disease
(COPD)
and Advance Directives

by

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Abstract

The purpose of this study was to determine if Chronic Obstructive Pulmonary Disease (COPD) patients use advance directives. Since the PSDA (Patient Self Determination Act) was passed in 1990, the use of advance directives has low numbers. This study utilized the model of Joyce Travelbees (Tomey & Alligood, 1998) human-to-human-relationship theory which emphasizes attaining a rapport with the patient after progressing through the original encounter, emerging identities, having sympathy and empathy. Twenty-five COPD subjects were given a quantitative cross sectional survey at a suburban hospital in Michigan, which included demographic information such as: age, gender, education, marital status and insurance. The subjects completed a self-report questionnaire about advance directives including questions such as: do you have an advance directive and who gave you information about advance directives. This study used SPSS (statistical package for the social sciences) for analyzing the data. The results showed that most subjects were>65 years of age, had a high-school education, were female, and were married. Results for this study also revealed that a high number of the subjects did not have an advance directive. Implications for theory, practice and research are related to the results. Of special importance is that healthcare workers, including nurse practitioners should continue to support advance directives in their professional practice.

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Chapter I

Introduction

Chronic Obstructive Pulmonary Disease (COPD) is defined by The American Thoracic Society as characterized by abnormal tests of expiratory flow that do not change markedly over periods of several months observation. An exacerbation of COPD can result in respiratory failure and death unless ventilator support is supplied. With mechanical ventilation (MV) at best, the patient will experience a few days of discomfort and if able to be removed from MV, returns to the preexisting level of disability and/or dies on an average within one year.

Current literature supports that COPD afflicts greater than ten million North Americans and is the fifth leading cause of death and major cause of disability (Dales, et al., 1999). COPD can eventually lead to severe physical, emotional, and social disability. Dales, et al., (1999) continue to say, that various studies to date range mortality between 20-73%, and that the COPD patients receiving MV cannot regain sufficient respiratory function to be extubated, and may die eventually from complications or remain connected to the ventilator indefinitely.

The limited life span for individuals with COPD means physical disability is probable as is mental decline followed by a period of terminal illness. It is clear that the future health of COPD patients is uncertain. COPD patients should have the opportunity to thoroughly understand that their wishes related to health care decisions will be addressed regardless of their physical or mental status. Against this background information about COPD affecting both physical and mental abilities of patients, advance directives become especially important.

An advance directive is clearly defined by Fischer, Alpert, Stoeckle, and Emanuel (1997) as having the right to refuse or authorize life-sustaining medical treatments. This right has been extended to decisions made in advance about future treatment in the event of decision-making incapacity. Basically, patients can ensure that their wishes are respected by completing a written advance directive that specifies the care they wish to receive if they should become incompetent.

All fifty states and the District of Columbia have enacted laws that govern advance directives (Haddad, 1998). The wording varies from state to state, but these laws allow a patient to create a document that stipulates what treatment he/she does or does not want if he/she becomes incapacitated. In most states, advance directives become effective when the patient is both mentally incapacitated and terminally ill. Patients can also help assure their wishes will be honored by signing a durable power of attorney for health care, which authorizes a surrogate decision maker or proxy to make decisions for the patient once he/she is unable to do so.

After an in-depth literature search on COPD and advance directives, one study linked the two content areas. As a critical care nurse in a major medical center for ten years, the investigator has purposely inquired and found only a few COPD patients with an advance directive. The literature review combined with clinical experience of the investigator helped to guide and focus this research project.

Tomey and Alligood (1998) use Joyce Travelbee's theory stating as professional nurse practitioners we can help assist the individual, family, and community to prevent or cope with the experience of illness and suffering, and to aid the person in finding a meaning to his/her experiences. Professional nurse practitioners care for clients with COPD and understand the course of illness is difficult and uncertain. Individuals can easily become mentally and physically incapacitated. To help assure their wishes about health care will be honored, advance directives are especially important to individuals with COPD.

The purpose of this research is to relate the chronic illness of COPD to advance directives and to ask this research question: Why do COPD patients not have advance directives?

Chapter II

Literature Review

Using Travelbee's human-to-human relationship model with COPD patients is appropriate. Travelbee's approach supports combining COPD with advance directives that provides a way to focus on refining empathy. Empathy is related to many concepts that aid nurse practitioners to assist clients with chronic disease. Travelbee gives a definition of empathy and other important concepts in her model as stated below.

1. Empathy- to be able to comprehend the psychological state of another.
2. Nurse-Patient relationship- the nurse possesses a body of specialized knowledge and is able to assist other human beings to prevent illness, regain health, and find meaning in illness.
3. Human-to-Human relationship- experiences between a nurse and the client. The major characteristic of these experiences is that the nursing needs of the individual or families are met. This human-to-human relationship is established when the nurse and the client in her care attain rapport after having progressed through the stages of the original encounter, emerging identities, empathy, and sympathy (Tomey & Alligood, 1998).

Examining the literature about COPD and advance directives is important to find ways to better understand how to be empathic in a nurse-patient relationship. Nurse practitioners use in-depth knowledge in their human-to-human relationships with COPD patients.

Chronic Obstructive Pulmonary Disease (COPD)

Most of the studies found were quantitative and spoke of COPD in terms of mechanical ventilation (MV) and the possibility of weaning, adding variables of infections, age, forced expiratory volume (FEV), and the stage of COPD.

COPD can be broken down into two subgroups: chronic bronchitis and emphysema. Barker, Burton, and Zieve (1999) define emphysema as:

> morphologic criteria as abnormal dilation of the terminal airspaces of the lung with destruction of alveolar septa in the absence of interstitial fibrosis. Chronic bronchitis is defined as a condition of chronic cough and sputum production for the majority of a one week interval, for at least three months of the year, for at least two years in a row which then excludes other disorders such as: bronchiectasis, tuberculosis, or cystic fibrosis (p. 694).

Risk factors identified by Barker, et al. (1999) state that cigarette smoking is the most prominent. Other risk factors include males over the age of 63, occupational dust exposure, and poor nutrition.

At some point and time, patients with end-stage COPD will need intubation and MV to sustain life. MV decisions are most effective when the patient and physician have discussed options in advance (Sullivan, Hebert, Logan, O'Connor, & McNeeley, 1996). The decision-making model in this study seemed to be physician driven. The fourteen respirologists emphasized the importance of knowing patients prior to initiating discussion on MV. The results concluded that the physicians indicated that the MV discussion usually took place when the possibility of an exacerbation was threatening and was too late in their opinion.

Patients who are affected by COPD undergo recurrent episodes of acute exacerbation of their disease, often requiring MV. Nava et al. (1994) looked at survival and failure or success of weaning from MV in forty-two COPD patients requiring MV for more than twenty-one days. The immediate recovery rate varied from 60% to 90%, while the survival rate after one year was quite low (34%-49%). The recurring rates and survival rates seem to be related to the fact that these patients are in the terminal phase of their chronic illness and their respiratory function and mechanics are severely compromised.

Research done by Rieves, Bass, Carter, Griffith, and Norman (1993) showed that MV for Acute Respiratory Failure (ARF) complicating COPD demonstrated an overall short-term mortality of 43%. This study was conducted over a five-year span (1987-1991), and included thirty-three men with severe COPD with a baseline FEV <1L. The researchers compared their results to other studies, which found 20-72% mortality of COPD patients who had been on MV. The researchers looked at several variables with these studies and found that the absence of pulmonary infiltrates on chest radiography and a higher baseline FEV had the strongest correlation to survival.

In a study done by Anthonisen (1989) age and baseline FEV were the best predictors of mortality for patients with COPD. This study stratified the patients according to baseline postbronchodilator FEV, analyzing groups with values of <30%, 30-39%, 40-49% and >50% predicted normal. The median age was sixty. In the group of

<30% and 30-39%, after controlling for age, FEV was still significantly related to mortality. The researchers compared their results with others and found that the best determinant of survival for COPD patients was age and degree of airway obstruction.

Menzies, Gibbons, and Goldberg (1989) stated the prognosis of patients with advanced COPD is poor. Among patients with COPD who are hospitalized with acute respiratory failure (ARF), mortality after one year ranges from 26%, if MV is not required, to 51-62% among patients who required MV. The researchers continue to say that in patients with COPD and ARF the decision to institute MV is difficult due to the high rate of complications, the risk of long-term dependence on MV and the uncertainty about the long-term prognosis.

Spicher and White (1987) did a retrospective review of medical records of two hundred and fifty patients with a minimum of ten days of MV during a five-year period. Their findings reported overall survival was 39.2% at discharge, 28.6% at one year, and 22.5% at two years. Of the patients who survived to discharge, 39.6% were placed in nursing homes and 32.7% were confined to their homes. The researchers concluded that prolonged MV is associated with a limited survival and poor functional status in many that did survive.

In a study done by Pearlman (1987), estimates of patient survival varied among physicians. He looked at patients with COPD and data in the medical literature describing prognosis. The researcher used a hypothetical patient that was presented to two hundred and five physicians and found 87% estimated the patient would live less than two years. Pulmonologists, who have the most expertise in this field, and represent the gold standard, provided a narrower range of survival (5-8 months). The scenario given to the physicians included measures of FEV, PaCO2 (partial pressure of carbon dioxide), baseline chest x-ray with evidence of COPD and requiring MV for ARF. The researcher concluded that physicians are an influential factor in medical decisions that involve individuals or elderly in end of life issues and additional education could narrow the gap on predicted mortality.

Burrows, Bloom, Traver, and Cline (1987) examined the course and prognosis of asthma versus COPD. The researchers compared the rate of decline in lung function and the mortality among patients whose initial features suggested chronic asthma with those patients who had more emphysema, obstructive type disease. Asthma (group I, non-smokers) was more favorable for prognosis than COPD (group II, smokers). The researchers compared group I and group II in a longitudinal study, and concluded that the ten year mortality follow-up of group II was close to 60 %, whereas group I was only 15%. The trend toward increasing mortality from group I to group II remained significant (p=0.02).

Gracey, Naessens, Krishan, and March (1992), looked at hospital and posthospital survival in 1986-1988 for MV patients for more than twenty-nine days. The authors concluded that prolonged MV is associated with limited survival and poor functional status. The overall values for probability of survival including hospital mortality after hospital discharge were 67.0%, 60.8%, and 56.5% at one, two and three years. After adding the conditions of multisystem failure and chronic lung injury, the mortality was high for this group after three years. Overall hospital mortality was greatest in the group older than sixty-five years of age and the least in the group younger than sixty-five of age.

In a recent study by Claessens et al. (2000), the researchers looked at severe COPD patients and stage III-IV lung cancer patients to understand more about prognoses and preference for outcomes and risks of treatment. Patients with COPD were more likely than lung cancer patients to receive MV (70.4% vs. 19-8%). The majority of patients (60%) in either group wanted comfort-focus care and 81% with lung cancer and 78% with COPD were extremely unwilling to have MV indefinitely. The researchers concluded that in caring for patients with severe COPD, consideration should be given to implementing palliative treatment, even while remaining open to provisions of life-sustaining interventions.

Advance Directives

Most of the literature found on advance directives referred to chronic, terminal disease, but not necessarily COPD.

Advance directives should be integrated as a part of preventive health care. Immunizations and other traditional preventive practices have become the standard of care. The same diligence is not used when it comes to talking about, or filing out an advance directive. Widespread support of advance directives is valuable to the health care system, but physicians are concerned that end of life decisions cause patients to become anxious or depressed. The elderly, by far, are the most likely to experience life-threatening illness and would definitely benefit from advance medical planning (Stafford, 1997).

A recent study has shown that despite widespread support of advance directives, only 4-24% of Americans have actually completed such a document. Knowing that it is impossible to predict a life-threatening event, physicians need to address advance directives with every patient during routine office visits and then follow-up annually, for opinions and circumstances change (Carney, & Morrison, 1997).

In a study conducted by Hughes and Larson (1991), procedural justice is introduced as a theoretical base to support the call for patient involvement in health care. The Group Value Model was used to explain the antecedents and consequences of procedural justice. It focused on the relationship between the individual and the group's authority figure and on the importance of group membership. The method used for this study was laboratory-based, using four written scenarios to manipulate the independent variable. The researchers compared the relative effect on outcome of a decision versus the effect of participation on three dependent variables: procedural justice, outcome satisfaction and physician competence. The researchers found that specific forms of participation can increase the procedural justice evaluation of a decision making process. They stated that by increasing procedural justice, this could increase patients' satisfaction with their health outcome and evaluation of the physician without increasing the resources committed to patients.

The study by Slevin, Plant, Lynch, Drinkwater, and Gregory (1988) stated that quality of life is a personal and individual question. The researchers used a questionnaire that was given to one hundred and eight patients and their doctors measuring quality of life, anxiety and depression and then used Kendall's concordance coefficient to analyze the results. Correlations between the two sets of scores were poor. The results emerged with two main points. The researchers point out that doctors were unlikely to determine how the patient feels and could not adequately measure the patients' quality of life. The researchers concluded that if a reliable and consistent method of measuring quality of life is needed, that patients should be the ones to decide for themselves.

Haddad (1998) stated that health care providers are legally and ethically obliged to follow advance directives, but several obstacles can get in the way of carrying out the patient's wishes. The researcher continued to discuss executional and decisional autonomy. Executional autonomy is the ability to carry out a decision; whereas decisional autonomy is the ability to make a competent decision. Patients in the hospital often lose their executional autonomy because of disease or injury. If their condition is severe, they may also lose decisional autonomy, for they are no longer able to reason or communicate their wishes. The Federal Patient Self-Determination Act (PSDA), applies to all health facilities that participate in Medicare and Medicaid, and requires that facilities inform patients of their right to execute advance directives (Requirements for Advance Directives, 1990). According to Haddad, statistics have shown that since the PSDA was passed, there has been little increase in the number of advance directives executed. Even when advance directives are put into place, the results show a lack of willingness on the part of health care providers to honor them.

The PSDA was passed in 1991 attempting to ensure that patients will be aware of their rights to make health care decisions and to refuse treatment, even after they have become unable to communicate their wishes. This process can be accomplished by informing patients about how to create an advance directive for health care. On admission, each patient will receive a packet of information on advance directives (Berrio, & Levesque, 1996).

Haynor (1998) points out that most patients seldom initiate the topic of advance directives. Healthcare workers need to remember that information we provide about advance directives raises many uncomfortable issues surrounding death and dying. Haynor continued to say that seventy-five percent of deaths in the United States are people >65 years of age, so most end-of-life decisions will involve them. Of this group of people, 30% do not have a spouse, family member or a friend to speak on their behalf. In cases that individuals do not have anyone to speak on their behalf, end-of-life decisions need to be the responsibility of health care workers. In complex situations, the courts are asked to appoint a guardian for the patient. Family opposition to advance directives, nonexistence of advance directives, and caregivers who disregard advance directives or failure to recognize advance directives all compound the complexity of end-of-life situations that include ethical issues for the nurse practitioner to face. Before healthcare workers can educate a patient on advance directives, we need to learn more ourselves about them. Healthcare workers need to be sensitive to spiritual and cultural beliefs, access to care, and the social status of the individual.

In a survey conducted by Deginer and Sloan (1992), four hundred thirty-six cancer patients and four hundred eighty-two members of the general public participated to determine what role people really want to assume in selecting treatment. Findings suggested that the impact of being diagnosed with life-threatening illness might influence preferences to participate. The majority (59%) of patients wanted physicians to make treatment decisions on their behalf, but 64% of the public thought they would want to select their own treatment if they developed a serious illness. Most patients (51%) and members of the public (46%) wanted their physician and family to share responsibility for decision making if they were too ill to participate.

Beisecker (1988) used a sample size of one hundred and six, forty-two males and sixty-four females, ages seventeen to eighty-five. This study concluded that patients in all age groups were relatively passive when interacting with the physician. Older patients

(>60 years) wanted less input in medical decision-making. The researcher's explanation for this conclusion comes from role theory. The researcher stated that older patients came of age during times when the doctor was a traditional power figure, someone to be revered and obeyed. The researcher continued with another explanation related to development; maybe as the person ages, he/she would want less responsibility for medical decisions and tend to rely more on the expertise of physicians. An additional explanation included the possibility that the aged are tired of assuming decision-making responsibility and are willing to defer to others. As stated by Haynor (1998), our population continues to grow and the elderly are living longer. The elderly account for the most deaths annually in the United States, so addressing end-of-life issues are increasingly more important.

Shoutton (2000) argues that nurses could contribute to better end-of-life care. Futile medical and nursing care is not only inefficacious but it may be harmful to the patient and also to health professionals, who may be diminished both as clinicians and as persons if they are unable to give appropriate care to dying patients and their families. The researcher examined futile care in intensive care units, because opportunities and temptations to provide futile care in this setting is higher than in nursing homes. Nurses can play an important role in initiating patient care conferences when they recognize the need to bring together the various parties to discuss end-of-life decisions. These conferences could then result in appropriate palliative care for the dying patients. The nurses providing care would be able to demonstrate their understanding of the process of dying.

Tilden, Tolle, Garland, and Nelson (1995), stated that despite the growing availability of advanced directives, most patients in the intensive care unit lack written directives, and, therefore, consultation with families about treatment decisions remains the rule. This study conducted interviews with family members of patients without advance directives whose death followed a stay in the intensive care unit. Themes emerged as families identified selected nursing and physicians behaviors as helpful: encouraging advanced planning, timely communication, clarification of family roles, and accommodating family grieving. Tilden et al. reported behaviors that made families feel left out or increased their burden included post-poning discussions about withdrawal treatment, delays in withdrawal, placing the full burden on one family member and defining death as a failure. The researchers also stated that the findings of this study provide an increased understanding of the unmet needs of families and this study should help guide health professionals in reducing actions that increase family's burdens as they participate in treatment withdrawal decisions. Finally, the data reflected the potential benefit of encouraging advanced directives for serious illness.

An interesting four-year project (Feinberg, 1997) entitled SUPPORT (Study to Understand Prognoses and Preference for Outcomes and Risks of Treatment) had a sample of ten thousand patients who were all in advanced stages of illness with a prediction of six months to live. The study contained information about individuals' desires for the type and extent of medical treatment that they wished to receive as their illness progressed. Unfortunately, contrary to their wishes, many received aggressive end-of-life support. Feinberg concluded that hospitals today focus more on cure than care. If individuals desire a calm and supportive atmosphere, they should be able to receive it. The researcher refers to hospice care stating that only 15% of Americans use these services. His suggestion for Americans is to push medical institutions to lessen the use of high-technology treatments and use palliative care when appropriate, especially when it is the person's wishes.

A study performed by Pearlman and Jonsen (1985), that used the patient management problem (PMP) was modeled after the American Board of Internal Medicine certification examination questions, which was developed to explore physicians' decisions to withhold MV. Two hundred and five internal and family medicine physicians were interviewed and their perceptions of the patient's quality of life demonstrated marked variability. Physicians considered the patient's quality of life more often to support decisions to withhold treatment than to support the use of MV ($p<0.01$). The authors concluded that in order to have successful intervention one must take into consideration quality of life in making life-and-death treatment decisions.

Fried and Gillick (1994), stated that when treatment options offered included alternative strategies such as to receive less intensive therapy, a significant number of elderly preferred this option. Their findings also suggested that a high number of patients (89%) surveyed, declined standard therapy during their final illness episode. The authors concluded that if alternatives are consistently discussed between physician and patient, pattern of decisions made by a previously competent patient could provide important information to help physicians and families decide appropriately for a person who can no longer participate in these decisions.

An interesting study by Hughes and Singer (1992), included mailed questionnaires to one thousand family physicians to examine their attitudes towards advance directives. Interesting enough, 86% of the physicians favored the use of advance directives, but only 19% had ever discussed them with more than ten patients. Another finding among these physicians was over half stated that they had not always followed the directions contained within the directive. Most of the physicians were in favor of offering advance directives to terminally ill or with patients who had chronic disease, but not to all patients who enter the hospital. The authors continued by stating that only 15% of people in the United States have completed an advance directive. The researchers' concluded that the physicians in their study reported that the most effective strategy to increase the use of advance directives would be public and professional education programs.

A study by Hanson, Danis, and Lazorick (1994) found the use of triage practice resulted in the use of intensive care for many more patients. The researcher's found that a majority of patients who die in the hospital received intensive care during their terminal phase. The researchers' found that patients admitted into intensive care received expensive and invasive treatments when they had orders to withhold extra-ordinary measures. Patients with severe chronic disease, cancer, and advanced age had mortality rates of 50-70% in the year following. Ethical guidelines now encourage health care workers to use patient preferences and many patients may deny hospitalization for acute illness. The problem arises when the patient chooses to be seen in the emergency room; triage decisions occur fast and rarely incorporate patient preference. The researchers' conclusion is that Primary Care Physicians need to elicit and record patients' preferences before the time of emergent decisions are to be made.

Concepts combined: COPD and Advance Directives

In a study done by Berrio and Levesque (1996) pulmonary patients were the focus. The pulmonary medicine unit used for this study saw COPD patients and watched their disease process progress. The researchers reviewed charts for a two-month span three years after the PSDA was instituted. All patient's had a poor prognosis and the researchers stated that the study participants would have been good candidates for an advance directive. The authors reported that only 17% (nine out of fifty-one) of those surveyed had filled out an advance directive. According to the authors, instituting advance directives is not hard, but actually getting one filled out is a problem. Healthcare workers felt that giving the information about advance directives would increase the number of patients who have one, but found out it is not that simple.

Gillick and Mendes (1996), stated as people reach old age and develop functional deficits, the probability of death in the near future increases, regardless of medical intervention. The researchers continued to say the risks associated with treatment such as infection, and MV, grows and the effectiveness of treatment declines. Taking this into account, it is possible that many people might wish to trade off maximal likelihood of cure for greater comfort, if offered the choice.

In summary, COPD research reviewed shows the staggering number of patients with COPD and how deadly and devastating this disease is. The literature reviewed shows aging people (60's) with COPD have a high mortality. Taking into account the initiation of MV brings their mortality even higher. Quality of life is different for everyone, but allowing patients to make an informed choice while they are still competent could make a world of difference for COPD patients.

The literature review regarding advance directives clearly shows a lack of knowledge for healthcare workers about advance directives including how to use advance directives with patients. Gillick and Mendes (1996) stated that people might select treatment that provides what they regard as an adequate chance of survival or success, even if that treatment is generally regarded as less than the standard of care.

Most of the literature reviewed pointed to further research that should be done to find out what patients want in regards to end-of-life issues. The biggest gap found was the necessity to give patients the education they need to make adequate decisions.

As stated in the previous literature, the PSDA has not shown a high compliance and should really be looked at further. Nursing and other health professionals can benefit from these studies by helping patients to identify their preferences and to make sound decisions for their end-of-life care. The literature points to the conclusion that it may be important when using advance directives with the elderly, that we need to educate them about their physical and mental functioning, the nature of their chronic illness that they might have, and their likely ending path. And to ask the research question: Why do COPD patients not have an advance directive? In addition, COPD patients over sixty-five have a high mortality which supports increasing the use of advance directives in this patient population.

According to Travelbee nurse practitioners can facilitate nurse-patient relationships by gaining specialized knowledge about how to assist COPD patients to make informed choices including being empathic to their psychological state (Tomey & Alligood, 1998). Thus, the purpose of this research is to further understand COPD patient's choices about whether or not they have advance directives.

Chapter III

Methods

A research design is the overall plan for obtaining answers to a research question (Polit and Hungler, 1999). The proposed research question is why do COPD patients not have an advance directive? A quantitative, cross-sectional survey was used for the purpose of answering the research question. This involves numeric information that results from some type of formal measurement and that is analyzed with statistics

Sample and Setting

A convenience sample of twenty-five patients was selected by using the following inclusion criteria: men or women, age 55 years or older and hospitalized for COPD. Exclusion criteria for this study were age <55 years, and in critical condition. The setting was a large suburban hospital in Michigan.

Instrument

The questionnaire consisted of two sides, one side of demographics and the other side with nine questions related to advance directives. The instrument used for this study was a quantitative questionnaire that had originally been developed by Marcy Welker FNP for use with patients who had more than one diagnosis at Hurley Hospital in Flint. With the permission of Marcy Welker, the tool was slightly revised to fit this study by excluding the topic of alcohol and a question about smoking was added. The final version of the instrument is in Appendix G.

Procedure

Initially the study was mentioned to Doctor Robert Begle, a Pulmonologist for the hospital and he was asked his thoughts and comments. Doctor Begle was asked if he would be willing to participate as the expert in COPD, and he verbally agreed. The next step was sending Doctor Begle a formal letter of intent of research being proposed (Appendix A). A letter to the medicine staff was sent requesting permission to utilize their patients throughout the hospital (Appendix B). A letter to the nursing staff was sent (Appendix C) where the research took place, explaining the study and asking for their cooperation. An additional letter was given to the subjects explaining the research and asking for their participation (Appendix D). A questionnaire was used for each selected COPD patient, after receiving informed consent (Appendix E). From December 1st-February 1st a self-administered questionnaire was used for each subject. Each subject was chosen from the Medicine Staff Team list. The hospital's human subjects committee gave approval for the study, as did the human subjects committee at The University of Michigan-Flint.

To protect the rights of human subjects, the principal investigator used a research assistant. The research assistant's background included: being a registered nurse, understanding the disease process of COPD, an interest and understanding of advance directives. The patients were approached by the research assistant to ask for participation in the study. If the patient agreed to be in the study, a consent form was signed and he/she could then be given the questionnaire about advance directives. The survey took approximately twenty minutes to complete.

Data Analysis

Data were entered in the database SPSS (statistical package for the social sciences) by PURA at the University of Michigan-Flint and were subsequently analyzed. Analysis used for demographics was frequencies. Cross-tabulations or contingency tables are two-dimensional frequency distributions in which the frequencies of two variables are cross-tabulated (Polit & Hungler, 1999). Crosstabs were conducted to see if there was a relationship between age and having an advance directive. Crosstabs were also used to see if there was a relationship between education and having an advance directive. Logistic regression was used to examine whether or not demographic variables and other selected variables were useful in predicting the answer to question number eight (Do you have an advance directive?).

CHAPTER IV

RESULTS

Demographics

The research question used for these results was: why do COPD patients not have an advance directive?

Twenty-five subjects participated in this study. Out of the twenty-five subjects fifteen were male (60%), and ten were female (40%). Within the sixteen questions used in the survey, 7 were related to demographics. Table 1 contains demographic results for age, education, race and marital status.

Table 1

Demographics (N=25)

		Frequency	Percent
Age	55-65	7	28%
	66-81+	18	72%
Education	Elementary	1	4%
	Middle	1	4%
	High-school	16	64%
	Trade/Tech	3	12%
	College-2yr.	4	16%
Race	African-American	4	16%
	Caucasian	16	64%
	Other	5	20%
Marital Status	Single	2	8%
	Married	11	44%
	Divorced	5	20%
	Widowed	7	28%

Table 2 contains results for gender, employment, and insurance.

Table 2

Demographics (N=25)

		Frequency	Percent
Gender	Male	15	60%
	Female	10	40%
Employment	Part-time	1	4%
	Retired	18	72%
	Disability	4	16%
	Other	2	8%
Insurance	Medicaid	5	20%
	Medicare	17	68%
	Private	19	76%
	None	0	0%

Note: The discrepancy result for insurance is because some people had two insurances.

Descriptive statistics are used to describe and synthesize data (Polit & Hungler, 1999). Question 8 on the survey states: Do you have an advance directive? This question was analyzed by using contingency tables to show a two-dimensional frequency distribution in which the frequencies of two variables are cross-tabulated. Table 3 shows gender; age, highest education level, and marital status when asked the question of do you have an advance directive.

Table 3

Demographic characteristics for individuals with advance directives.

(n=25)

		Do you have an advance directive?	
		NO	**YES**
Gender	Female	4	6
	Male	12	3
Age	55-59	4	0
	60-65	3	0
	66-70	1	1
	71-75	4	3
	76-80	2	4
	81+	2	1
Education	Elementary	1	0
	Middle	1	0
	High-school	9	7
	Trade/tech	1	2
	College/2yr	4	0
Martial Status	Single	2	0
	Married	7	4
	Divorced	4	1
	Widowed	3	4

Table 3 shows that females were more likely than males to have an advance directive (female, 6/25, 24%, males, 3/25, 12%). The males in this study show they do not have an advance directive compared to women (males, 12/25, 48%, females, 4/25, 16%). The age group 55-65 did not have an advance directive (0%). This survey suggests that for those in the age group 66-81+ (9/18, 50%) were more likely to have an advance directive, when compared to those 65 and younger. The education category suggests that having a higher education does not necessarily influence their decision to have an advance directive. The martial status category also suggests that there may not be an influence in this category to whether or not individuals have an advance directive.

Logistic regression was used to examine relationships between demographic variables and whether or not participants had advance directives (Table 4). In addition, selected variables for receiving printed material (Question #5) and encouraging this type of planning (Question #6) are shown in table 5 below.

Table 4

Variables in the equation.

Logistic Regression for demographic variables and advance directives status.

	SE	Wald	Sig.
Age	.511	1.989	.158
Marital Status	.707	.149	.699
Education	.801	.320	.571
Race	.486	.076	.783

Table 5

Variables in the equation.

Logistic Regression for material/planning and advance directives.

	SE	Wald	Sig.
Printed Material	3.699	.947	.330
Encourage Planning	1.942	1.170	.279

Note. Wald statistics refers to: In logistic regression, a Wald statistic is used to evaluate the significance of individual predictors (Polit, 1996).

A z-test for the standard error of a proportion was used for the final results of answering the proposed research question: Do you have an advance directive? The results show that 16/25 (64%) stated "no" to having an advance directive. When computed with the standard error of the mean (.098), the z-statistic was 6.53. Significance at the .05 level should be at 1.96 or beyond. This result supports the conclusion that a significant number of the COPD patients surveyed for this study do not have an advance directive.

Percentages for categories in question #3 regarding either a family physician or another healthcare professional discussing advance directives with the study participants were 96% "no" for both categories. Individuals who had heard of advance directives (56%) acquired their knowledge through a family member (spouse, and/or children).

Chapter V

Discussion

Interpretation

Joyce Travelbee's human-to-human relationship model with COPD patients was used for this study. Travelbee's approach supports combining COPD with advance directives that provides a way to focus on refining empathy. Empathy is related to many concepts that aid nurse practitioners to assist clients with chronic disease. Travelbee (Tomey & Alligood, 1998) gives a definition of empathy and other important concepts in her model as stated below:

1. Empathy- to be able to comprehend the psychological state of another.
2. Nurse-Patient relationship- the nurse possesses a body of specialized knowledge and is able to assist other human beings to prevent illness, regain health, and find meaning in illness.
3. Human-to-Human relationship- experiences between a nurse and the client. The major characteristic of these experiences is that the nursing needs of the individual or families are met. This human-to-human relationship is established when the nurse and the client in her care attain rapport after having progressed through the stages of the original encounter, emerging identities, empathy, and sympathy.

Examining the literature about COPD and advance directives is important to find ways to better understand how to be empathic in a nurse-patient relationship. Nurse practitioners use in-depth knowledge in their human-to-human relationships with COPD patients.

The z-test findings were significant. The results indicated that 16/25 (64%) individuals in the sample stated "no" to having an advance directive. These results show the need for nurse practitioners to stand up to the plate and take a stand. By using Travelbee's model to help and better understand COPD patients, we first need to establish a rapport with the patient. Continuing with sympathy and empathy will enable the nurse practitioner to establish the human-to-human relationship.

Tomey & Alligood (1998) continue with Travelbee's model stating that at some point in a person's life, he/she will be confronted by illness and pain (mental, physical, spiritual), and eventually he/she will encounter death. The literature review pointed out the staggering morbidity/mortality facts about COPD. The knowledge gained from this study assists nurse practitioners to have a more empathic approach by assisting COPD patients to find meaning in their experience to illness and suffering.

The focus of nursing has changed from disease entity approach to a more holistic approach. Advance practice nurses have the education to address the holistic individual also including the emotional and spitural needs of the patient. End-of-life issues are a sensitive matter and quality and quantity of life is different for each individual. Healthcare professionals, including nurse practitioners, must take into account all aspects of individuals to meet their end-of-life decisions. We must put aside our personal feelings and approach each patient in an individual, holistic, and empathic manner.

Validity

The principal investigator found that upon talking with patients about their understanding of advance directives, most of the subjects really did not understand what an advance directive was. The researcher concluded that the validity of the findings for the question about "Do you have an advance directive?" may have been a higher number than the 64% of no responses due to the fact the subjects thought the living will was the same as the advance directive. The researcher has identified that more explanation needs to be given to the patients about advance directives to make a more informed choice.

Implications

Implications related to age, gender and education from the findings are in Table 3 and Table 4. The results suggest further education is needed to better explain advance directives to patients (64%). There is also a need to further implement the necessity of healthcare workers to talk about advance directives with their patients. A recent study has shown that despite widespread support of advance directives, only 4-24% of Americans have actually completed such a document. Knowing that it is impossible to predict a life-threatening event, physicians and nurse practitioners need to address advance directives with every patient during routine office visits and then follow-up annually, for opinions and circumstances change (Carney, & Morrison, 1997).

The principal investigator found that when asking the question: did a family physician or healthcare professional discuss advance directives with you 96% stated "no". The investigator found that the people who had heard of advance directives (56%) acquired their knowledge through a family member (spouse, and/or children). The study by Hughes and Singer (1992) included mailed questionnaires to one thousand family physicians to examine their attitudes towards advance directives. Interesting enough, 86% of the physicians favored the use of advance directives, but only 19% had ever discussed them with more than ten patients. The authors continued by stating that only 15% of people in the United States have completed an advance directive. The researchers' concluded that the physicians in their study reported that the most effective strategy to increase the use of advance directives would be public (local and state) and professional education programs.

Joyce Travelbees model including empathy, nurse-patient relationship and human-to-human relationship seems to fit this group of individuals. As advance practice nurses we can use all concepts from this model to aid patients in their illness and end-of-life issues by discussing advance directives with them.

Alternative Explanations

Looking at the results of the study, the researcher concludes that most of the patients surveyed had a high school diploma, but would there be different results if the patient had more education? Taking the education piece further: what kind of answers would the researcher have received if the survey was given to someone in the lower socioeconomic status?

The literature supports that even though the PSDA was passed, the figures are extremely low to filling out an advance directive. Wenger, et, al. (1994) stated the PSDA requires hospitals and certain other health care agencies to provide adult patients with written information about their rights to accept or refuse treatment and to prepare advance directives. The researchers concluded that hospital admission may not be the optimal time to advise patients about their ability to participate in health care decisions. Patients generally have a heightened interest in their health care when they enter the hospital, but they may be distracted, in distress, stressed, or even incapable of making decisions at time of admission. Allowing the patient to make a decision prior to admission would be a better approach. This is a sensitive matter and needs to be approached in a non-threatening, caring, and empathic manner.

A patient's inability to understand advance directives may explain why so few have signed the document. A study conducted by Ott, & Hardie (1997) found that the advance directive document is difficult to read. The researcher found that these documents were written several levels above the reading level of the average patient. Nurse practitioners have a key role in initiating and distributing written information about advance directives. If we continue to refine advance directives, this document will become easier to understand and therefore more useful in supporting patients wishes and autonomy.

Limitations

In order to have a representative sample, the researcher would need to collect data from the entire population (Polit & Hungler, 1999). One of the limitations for this study was the small sample size. During data collection the investigator found that many patients who responded "yes" I have an advance directive also thought it was the same as a living will. The investigator made the decision to use their responses to the questionnaire in the data analysis. Another area of limitation was this study was done at a suburban hospital, all of the patients had insurance and the majority were Caucasian and female.

Recommendations

Recommendations for future study include: a larger sample size, and random sampling of participants. Future research should include a better definition of advance directives with a screening question to see if participates understand the definition. Other recommendations are to include more men and a more ethnically diverse sample. Also including uninsured participants is important. Using these recommendations would give a better generalized idea of subjects that do, or do not have an advance directive.

Conclusion

The study conducted by the investigator is important because it brings more attention to a topic that has been ignored for too long. This literature review about COPD patients has shown there is a definite need for education with this group of people. As an upcoming nurse practitioner, our continued effort to help patients with chronic disease is important to provide quality care. As stated by Dales et al. (1999), there are ten million Americans alone with COPD and with our population living longer lives, we need to support and educate these individuals to aid them in healthy choices. Knowing more about how to assist individuals to make choices about advance directives is a worthy research effort.

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Appendices

Appendix A

Appendix A

Letter sent to Doctor Begle

Date: 06/08/2001
Dear Doctor Begle:

A few months ago, I approached you on a research study that I would like to conduct. This letter is to inform you of the proposed research question and again to ask you for your expertise and participation in this study, as a member of my thesis committee.

As we had discussed previously, the proposed question is: Why do many Chronic Obstructive Pulmonary Disease (COPD) patients not have an advance directive? Your interest in this area and expertise guided me to selecting patients on the pulmonary floor (6 central), to complete a questionnaire.

Thanking you again for agreeing to be on my committee for this project.

Thanking you in advance for your cooperation, support, help and interest in this study.

Detailed information and progress about the study is available to you upon request.

Sincerely,

Melody Williams
Principal Investigator

Returning the following page with your signature acknowledges receipt of this letter. Returning the following page (to me personally or through interdepartmental mail) at your earliest convenience would be appreciated. Thank-you.

Appendix B

Appendix B
Letter to Medicine Staff Team

Dear Medicine Staff Team:

I am currently a registered nurse (BSN), who works in the MICU (Medical Intensive Care Unit) and am working towards my degree of Family Nurse Practitioner (FNP). This letter is to ask for permission and consent to approach your patients on the sixth floor (central) with the diagnosis of Chronic Obstructive Pulmonary Disease (COPD) for the purpose of my research study.

With the help of Doctor Robert Begle, I am planning on doing a quantitative study using a questionnaire (attached) to gather information about why COPD patients do not have an advance directive.

In order to accomplish my research, I am asking for your participation by using your list of patients with the diagnosis of COPD who will be located throughout the hospital. Brynn Fields, RN. BSN will ask you for a list of your patients. Brynn will use this list to determine who can be approached and she will invite patients to participate in my study. Detailed information and results on the study are available to you upon request.

Data collection is from October 1st - December, 2001. Response to agreement can be done with the attached consent and sent to me via in-house mail to MICU.

Thanking you in advance for your cooperation and support.

Melody Williams RN.BSN.

Principal Investigator

Appendix C

Appendix C
Letter to the nursing staff on pulmonary floor

To the staff on 6 central

As part of my advanced degree for MSN-FNP, Doctor Robert Begle and the Medicine Staff Team will be working with me, Melody Williams, RN, BSN, from the University of Michigan-Flint, by doing a quantitative study with the use of a questionnaire. This letter is to ask for your cooperation and to give you information on the proposed study that will be done on your floor.

The current focus is selecting patients with the diagnosis of Chronic Obstructive Pulmonary Disease (COPD) and giving them a questionnaire about advance directives. The research questionnaire should not take more than 20 minutes and will be delivered and picked up 24 hours later by me. The patients will be selected from a list provided by the medicine staff team, with the diagnosis of COPD.

I would like to collect data on 6 central to begin November 21st , 2001 and end approximately December 31st, 2001. Patients who participate in the study have the right to refuse to answer any questions if they wish, or to withdraw their participation at any time.

Your support in my research is greatly appreciated. Any questions about the study please feel free to contact me personally. Melody Williams 248-969-0462, or ext. 14800 (4 east-MICU).

Thanking you in advance for your cooperation.

Sincerely,

Melody Williams, RN, BSN.
Medical Intensive Care (MICU)

Appendix D

Appendix D
Letter to Patients

Dear Mr., Mrs., Miss, Ms.,______________________________________
(Brynn will write name in blank)

My name is Brynn Fields and I would like to invite you to participate in a research study being conducted by another nurse, Melody Williams, RN, BSN, who is a student in the Graduate Nurse Practitioner Program in the Department of Nursing at the University of Michigan-Flint. This research is about Chronic Obstructive Pulmonary Disease (COPD) and Advanced Directives. The sample will include male and/or females with the diagnosis of COPD.

Participation in this study includes completing a questionnaire that asks you to provide demographic information about yourself and has questions referring to whether or not you have an advanced directive. It should take no longer than 20 minutes to complete. I hope you will agree to participate. The questionnaire will be delivered by Melody Williams who will also ask you to read and sign a consent form. Then, after 24 hours the questionnaire will be picked up by Melody Williams. Your responses are extremely important for this study.

Your responses will be kept confidential. Neither your name nor any other identifying information will appear on any of the materials used in this study. All information you provide will be analyzed as group data and no individuals will be identified.

Participation is voluntary. You may discontinue participation at any time without penalty. Your refusal to participate in this study will not affect you or your care as a patient in any way. You will continue to receive the highest quality care regardless of your decision about participation in this study.

Final results of the study will be shared with the University of Michigan-Flint and the hospital, but no identifying factors about you will be disclosed.

If you have any questions, Brynn Fields will inform me and, I will be available to respond to your questions.

____

Sincerely,

Melody Williams, RN, BSN.
Principal Investigator
The University of Michigan-Flint
Department of Nursing
517 French Hall
Flint, MI. 48502
810-762-3420

Appendix E

APPENDIX E
ADVANCE DIRECTIVES SURVEY

It is a patient's right to authorize or refuse life-sustaining medical treatment. A patient's wish about life-sustaining medical treatment is respected by completing an advance directive document. An advance directive specifies the care patients wish to receive if they should become incompetent.

When you first entered the hospital you were given a packet on advance directives. In addition to the packet, this survey is a continuation of information on the subject of advance directives.

Participation in this survey is voluntary, and will in no way affect care you receive from the hospital. You may skip questions that you do not wish to answer. All information collected in this survey will be kept strictly confidential. Please answer the following items by placing an **X** on the appropriate line.

Gender
____**Male**
____**Female**

AGE
____**55-59**
____**60-65**
____**66-70**
____**71-75**
____**76-80**

Marital Status
____**Single**
____**Married**
____**Divorced**
____**Widowed**

Education (highest)
____ **Elementary**
____ **Middle**
____ **High School**
____ **Trade/Technical**
____ **College-2yr.**
____ **College-4yr.**
____**Post Graduate**

Employment
____**Part time**
____**Full time**
____**Unemployed**
____**Retired**
____**Disability**
____**Other**

Insurance
____**Medicaid**
____**Medicare**
____ **Private**
____**None**

Race
____**African American**
____**Asian**
____**Caucasian**
____**Hispanic**
____**Native American**
____**Other**

1. Do you have a regular family or primary care physician?
(If "No", go to Number 3)
____Yes ____No

2. Approximately how long have you been a patient of his/hers? ______

3. Have you discussed advance directives with any of the following persons?
(Please answer each question with a "Yes" or "No").

	Yes	No
A friend?	___	____
Your spouse?	___	____
Your children?	___	____
Other family member?	___	____
An attorney?	___	____
Your family physician?	___	____
Another healthcare professional?	___	____
Other person(s)?	___	____

4. If "Yes" for family physician or "another healthcare professional":
Who brought up the topic or started the conversation?
(If "No", go to question number 5)
____Me ___physician/healthcare professional
____Spouse/family member

5. Did a physician or healthcare professional give you any printed materials or pamphlets about advance directives?

____Yes ____No

6. Did a physician or healthcare professional encourage you to consider this type of planning?

____Very much ____Somewhat ____Not at all

7. How well do you feel that you understand advance directives?

____Very Well ____Somewhat ____Not at all

8. Do you have an advance directive?
____Yes ___No

9. Regarding tobacco, did/do you smoke?

In the past? ____Yes ____No
Currently? ____Yes ____No